Supporting The Neonatal Nurse In The Role Of Final Comforter

By: **Amber Welborn, MSN, RN, Staff Nurse, Lecturer**

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Supporting the neonatal nurse in the role of final comforter

Amber C. Welborn, MSN, RN, Staff Nurse, Lecturer

The University of North Carolina at Greensboro School of Nursing, USA

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Comfort

Abstract The death of an infant in the neonatal intensive care unit (NICU) without the presence of family members can be a stressful event for the care nurse, who may feel obligated to provide love and comfort to the infant, in addition to medical care. The nurse may experience role conflict while attempting to meet all of the infant's perceived needs. This article explores the unique needs and circumstances of the NICU nurse in the role of final comforter for a dying infant when a family member is not present. The provision of such emotionally demanding work requires the nurse to receive education, mentoring, and support from colleagues and administration. NICU nurses who receive education on grief management and palliative care, mentorship from experienced nurses, and post-mortem grief support are better able to manage their own experiences with grief after the death of an infant in their care.

Many nurses working in a neonatal intensive care unit (NICU) have been asked, "How do you handle taking care of those sick babies?" This is a well-meaning question, but most NICU nurses do not consider caring for critically ill babies and their families a burden (Discenza, 2014). NICU nurses verbalize intense feelings of guardianship and protection toward their patients and frequently refer to them as "my babies." In order to provide and experience such affection, the nurse must become emotionally vulnerable. This article explores the unique needs and circumstances of the NICU nurse caring for a dying infant when a family member is not present to provide comfort. Educational and practice strategies that promote optimal infant care and support for healthcare team members surrounding the death event are offered.

NICU nurses hold a unique vantage point, a perspective that is different from the infant's family or other healthcare team members (Discenza, 2014). The nurse's clinical judgment considers all

facets of physical, developmental, and family-centered needs. Nurses engage with every medical device, ancillary specialist, and family member. The nurse interprets data with the medical team, listens to the concerns of the family, and offers suggestions to members of the healthcare team. This interconnection allows the nurse to form a holistic view of the baby's strengths and needs; the result is highly individualized, expert plans of care. When the baby is progressing or struggling with milestones, the nurse offers distinctive insight.

NICU nurses often become personally invested in the welfare of the babies for whom they provide care. Once emotionally invested, NICU nurses usually experience sadness and grief if the baby decompensates or dies (Lee and Dupree, 2008). These raw human emotions are difficult to navigate at any time, but the NICU nurse may experience them while providing direct nursing care to a dying infant. This emotional experience may be deepened if a family member is not present in the time surrounding death.

Background and significance

Approximately 4% of infants die within the first 28 days of life, with most deaths occurring in a NICU and resulting from a complication related to low birth-weight and/or prematurity (Child Health USA, 2013). Various scenarios may lead to infant death, including but not limited to birth defects, prematurity, and maternal complications of pregnancy (CDC, 2015). Death may be anticipated by precipitating events, such as traumatic delivery, extremely low-birth weight, multi-system organ failure, or a planned withdrawal of medical support; or death may be completely unexpected.

Neonatal death is devastating and stressful for families and healthcare team members (Epstein, 2010). Death is more distressing for the care team when the infant dies without the presence of family. Geographic or situational circumstances may prevent family from being with the infant at the time of death. Parents may feel unable to experience the emotions of witnessing the death or withdrawal of care. Some parents choose to relinquish custody early in the infant's life without choosing a designated caregiver. Alternatively, death may occur suddenly and unexpectedly in the absence of family.

In most situations, when a baby dies without the presence of a family member, the NICU nurse assumes the role of final comforter to the infant. The assumption of this role may be initiated by the nurse near the time of death or previously assigned to a nurse by the family. NICU nurses exclusively provide almost all of the hands-on care and are an integral participant in the planning of care. Nurses are at the infant's bedside 24 hours a day providing optimum care and comfort, especially in the time surrounding death. Anecdotal evidence suggests nurses feel an obligation to comfort a dying infant. The provision of such emotionally demanding work requires the nurse to receive education, mentoring, and support from colleagues and administrators.

Literature review

NICU nurses experience the tragic circumstance of infant death on a regular basis. The nurse is challenged to provide direct nursing care while simultaneously attempting to meet the perceived comfort needs of the baby. Support of nurses during and after an infant's death promotes their mental and emotional health, prevents burnout, and supports their ability to provide quality patient care (Adwan, 2014; Kain, 2012; Lee and Dupree, 2008; Martin, 2013; Mendel, 2014). The literature offers suggestions to support families and physicians during the experience of infant death and dying; however, there is a dearth of literature addressing the specific support needs of nurses caring for a dying infant without the presence of family. The nurse's role is dramatically altered when caring for a dying baby in the role of final comforter, as compared to their role when parents are present at the bedside.

Grief as a part of the nurse's role

Nurses must identify a therapeutic approach to grief management and grief support of colleagues as a part of their daily work (Stayer and Lockhart, 2016). The literature identifies several themes related to care-related grief which may be magnified for the nurse in the role of final comforter. Caring for critically ill babies is stressful and emotionally intense in the high-mortality and high-stress environment of the NICU (Lee and Dupree, 2008; Mendel, 2014; Stayer and Lockhart, 2016).

Although sadness is the most commonly cited emotion in the literature, this feeling has been viewed positively as a marker of "humanity and emotional availability" (Lee and Dupree, 2008, p. 988; Stayer and Lockhart, 2016). Younger and less experienced nurses may find these feelings to be even more extreme, as they usually have less life experience and fewer coping mechanisms to help

them navigate intense sadness and grief (Myhren et al., 2013; Zander et al., 2010).

Caring for critically-ill children, especially in the absence of their parents, is a unique experience best shared by colleagues who have felt this common emotional burden (Kain, 2012; Lee and Dupree, 2008; Macpherson, 2008; Mendel, 2014). Nurses caring for dying children report an overall lack of support while navigating the grief process; that their grief is not recognized or acknowledged (Kain, 2012; Lee and Dupree, 2008). Yet, nurses feel an intense desire for acknowledgment of their grief by colleagues (Kain, 2012). The lack of opportunity to discuss their loss with peers results in anger and disappointment towards their colleagues (Kain, 2012). Nurses who report feeling unsupported or ignored verbalize intense negative feelings even years later (Anderson et al., 2015).

Moral obligation of facilitating a "good" death

Using a hermeneutic phenomenological approach to explore the experiences of 11 neonatologists and 24 NICU nurses, Epstein (2010) found that physicians and nurses share similarities in their feelings and desires surrounding the care of a dying infant. The common theme uncovered through content analysis was their desire to provide comfort to the dying infant.

Mendel (2014) proposes that definitions of "good" end-of-life care are variable within the literature, yet most agree that nurses feel compelled to balance beneficence and non-maleficence. Nurses feel a moral obligation to advocate for the infant and provide the best end-of-life care possible by providing pain control, a supportive environment, and emotional comfort. Patient advocacy to reduce or eliminate painful and unnecessary procedures, such as heel sticks, venipunctures, and procedures, is paramount to achieve non-maleficence. Provision of appropriate pain control and sedation, despite respiratory side effects, and providing physical comfort through nesting, low-stimulation environment, and gentle touch are examples of beneficence (Epstein, 2010; Mendel, 2014; Stayer and Lockhart, 2016). The experience of providing warmth and love, particularly through holding the infant, is essential to minimize suffering (Epstein, 2010). Fulfillment of beneficence and non-maleficence align with Epstein's (2010) holistic description of "providing comfort."

Cultivating a personalized environment of the baby's own clothes or blanket, pleasant-smelling lotion, and/or gentle music may add to the creation of a peaceful death (Gerow et al., 2010; Stayer and Lockhart, 2016). The nurse may feel a greater burden to independently define and create an environment that is comforting and loving for the infant in the absence of a family member's input. The nurse relies only upon their personal and professional experiences and intuition in this situation (Copnell, 2005). Novice nurses, who have had fewer encounters with death and dying, may feel ill-equipped to plan palliative nursing care. Afterward, they may doubt the decisions they made, further complicating the grief experience (Anderson et al., 2015).

Role conflict

The planning and implementation of care for a dying infant involves the entire healthcare team. Nurses strive to provide care that supports the infant, yet meets the expectations of the guiding physician. While some guidelines for palliative care for neonates exist, often the recommendations are not consistently followed due to the uncomfortable shift from curative to comfort care (Mendel, 2014).

When the nurse is the only available comforter for the infant, role conflicts may ensue. At some point, a single nurse will not be able to simultaneously meet expectations of the physician orders and facilitate the activities needed to meet the nurse's criteria for a "good death." The nurse must choose between the tasks required to implement medical orders and the desire to focus on comforting the baby, particularly by holding the baby (Epstein, 2010; Mendel, 2014). Nurses become frustrated and sometimes angry when they feel they do not have the opportunity to provide a "good death" (Martin, 2013; Stayer and Lockhart, 2016). Internal conflict and limited opportunities for decision-making are linked to decreased job satisfaction and increased risk for burnout (Adwan, 2014; Mendel, 2014; Myhren et al., 2013). Burnout may extend beyond job dissatisfaction and lead to the intention of withdrawing from the nursing profession altogether (Adwan, 2014).

Debriefing

The literature is inconclusive regarding formal debriefing as a supportive tool. The individual's level of participation and timing of the sessions are important factors to consider. Keene et al. (2010) found overwhelming support for debriefing following a pediatric death, with almost all

respondents (n = 184) reporting debriefing as helpful. Post-intervention surveys indicated a positive correlation between the level of participation in debriefing and the individual's ability to successfully manage their grief.

However, the timing of debriefing is a key factor in its success as a support strategy. Nurses have already progressed through much of the grieving process after a few days or a week following the death (Kain, 2012). The nurse may feel worse if debriefing reopens a partially-healed emotional wound. In addition, nurses expressed resentment over the burden to initiate a group discussion and the expectation to participate in a debriefing session during non-working or inconvenient hours (Kain, 2012).

Informal debriefing and story-telling with colleagues has been found overwhelmingly helpful. Nurses must actively listen to others and share stories of their own to experience the full benefit of grief mitigation (Macpherson, 2008). Sharing similar experiences and emotions regarding the care of dying children increases a feeling of community and teamwork. Many nurses report that this feeling of shared experiences allows them to work in a stressful area of nursing for a longer period of time than if they feel isolated in their grief (Aycock and Boyle, 2009; Stayer and Lockhart, 2016).

Recommendations for future practice

It is important for nurses to receive support throughout their entire grief process. Opportunities exist at all levels to educate and support the nurse. Even before a baby dies, anticipatory grief preparations may be provided through education, story-telling and discussion, and experiences with preceptors. At the institutional level, support may be demonstrated through establishing policies that provide for grief counseling and education. Staff can support one another through mentorship and peer support. A variety of options should be available to allow nurses to select the support that best fits their personality and grief experience.

Preparing the nurse

Nurses must be encouraged by nursing leadership and peers to practice self-care as an integral part of grief management. Utilization of time off for activities that bring the individual joy and rejuvenation may help the nurse better respond to the needs of peers and families. Emotional decompression through physical activity and adequate sleep may be helpful in separating work and home life. Engaging in positive problem-solving and active listening with peers promotes the development of support systems. Laughter and the appropriate use of humor, or a quiet time alone with meditation or yoga, can all help combat cumulative grief and compassion fatigue (Aycock and Boyle, 2009; Houck, 2014).

As a part of orientation to the NICU nurse role, nurses should be made aware of the potential of an infant death and differences in nursing care when families are absent. During the novice nurse's orientation period, nurse preceptors should engage in general discussion of neonatal palliative care, expectations of the bedside nurse, and explore common concerns related to caring for a dying infant (Anderson et al., 2015; Mendel, 2014). Early exploration of grief coping mechanisms and education in self-care assists the nurse in identifying positive means to cope with major stressors, including experiencing the role of final comforter to a baby.

A proactive approach is helpful in the overall navigation of grief (Conte, 2011; Hildebrandt, 2012). Identification and refinement of coping strategies should be a part of annual continuing education. Novice and experienced nurses engaging together in group discussion helps to identify effective and ineffective coping mechanisms (Myhren et al., 2013; Zander et al., 2010). Experienced nurses may reflect upon intense feelings from their experiences as final comforter, providing empathy and insight to those with less experience. They may also unveil an unresolved negative emotion, sensitivity, or vulnerability from a prior experience of caring for dying infant. Through these approaches, opportunities for individual counseling may be highlighted.

It is helpful for novice NICU nurses, especially those with less nursing or life experience, to assist a more experienced nurse in providing care as final comforter for a dying baby. The novice nurse participates in care planning in anticipation of the infant death and is simultaneously exposed to the emotional environment created by the event. The novice nurse does not independently provide care in this instance, although they may assist in the infant's care. The focus of the novice nurse is to watch the experienced nurse, absorb the complexity of the care plan and emotionally process the event. Advantages exist for both nurses in this situational mentorship. The experienced nurse has extra help for task management, allowing their primary focus to shift towards comforting and holding of the baby sooner. The novice nurse is provided the venue to brainstorm and discuss the

complex care plan with an experienced colleague. This mentorship opportunity provides the novice nurse a supportive environment to serve as a positive, formative experience of caring for a dying infant. Experiencing death in a context that does not emotionally devastate the novice nurse provides a healthy basis for future experiences of caring for dying babies (Anderson et al., 2015; Gerow et al., 2010).

Studies by Gerow et al. (2010) and Anderson et al. (2015) uncovered similar themes stating formative experiences with patient death are significant in setting a foundation when caring for future dying patients. Nurses who felt unsupported and left to grieve alone were emotionally traumatized, avoiding circumstances that reminded them of the experience. However, if the nurse had a positive role model or mentor, felt supported, and received positive coaching, they expressed feelings of team inclusion and self-pride (Gerow et al., 2010; Anderson et al., 2015). Ultimately, positive experiences may reduce burnout and promote nursing unit and professional retention (Adwan, 2014; Conte, 2011).

Supporting the nurse while caring for a dying infant

The nurse caring for a dying infant always needs support, but will require additional support in the absence of the infant's family. This nurse will likely feel obligated to love and comfort the infant, in addition to providing nursing care, which may cause the nurse to experience role conflict (Epstein, 2010; Mendel, 2014). Colleagues should engage the nurse in open communication about this conflict to ascertain what role the care nurse wishes to maintain and the role that another nurse should assume. Care planning to divide the responsibilities of nursing care should specify who will provide physiological support, and who will hold and comfort the baby.

Early communication with the hospital chaplain will help to clarify the spiritual care needs of the baby and care nurse. Without clear communication, the chaplain may assume their focus will be comforting the baby's family, rather than supporting the bedside nurse. The pastoral community reports eagerness to support grieving nurses, but are not usually made aware of the need. Nurses may be offered a simple "blessing of hands" and a prayer for their continued care for the smallest of patients (Aycock and Boyle, 2009). Alternatively, the nurse may prefer the quiet physical presence of a chaplain over any words at all.

Delegation of specific tasks, such as documentation of patient status changes, can assist the nurse with time management. Through appropriate delegation, staff will have a clear understanding of each person's duties and when they can comfortably assume their assistance is no longer needed. A plan of communication through the call bell or wireless phone will ensure quick attention from peers if additional help is required. The charge nurse should redistribute the nurse's remaining assigned patients to other staff. Prioritization of medical orders will encourage the focus of nursing care toward primarily comforting the baby. Privacy for the care team, specifically the nurse who is holding the baby, may facilitate more effective communication and a cohesive plan of care (Epstein, 2010).

The nurse will need practical support from colleagues while holding the baby for a potentially long period of time. This support may include notifying the nurse's own family of a probable delay in their arrival home, or temporarily holding the infant to provide the nurse a meal or restroom break. Locating a suitable chair or readjusting a pillow will assist this nurse to be comfortable for longer. Another nurse or team member should accept the role of liaison to others nearby if the infant is not in a private room. Depending on the layout of the NICU, nearby families of other infants and support staff may see and hear unusual activities. A liaison can provide comfort and reassurance to those families and staff.

Emotional support for the nurse

Nurses who have cared for a dying infant verbalize the intense desire to feel that their grief is recognized by peers. Kain (2012) found that even long-time co-workers may not effectively recognize that their colleague is grieving or distressed in the workplace. Overt acknowledgment that a loss has occurred and not discounting or abbreviating the situation is essential in supporting the nurse (Anderson et al., 2015; Kain, 2012; Lee and Dupree, 2008). Simple recognitions of loss and condolences are beneficial (Kain, 2012). Verbal statements such as, "I'm sorry this baby died. How are you doing?" may be meaningful. Acknowledgements to a nurse as final comforter such as, "That baby was lucky to have you as a nurse. You were so kind and loving." may be especially comforting. A gentle hand on the shoulder or hug may be appropriate between team members that have an established relationship. Missed opportunities to acknowledge and

support nurses early in the grief process may result in negative relationships within the unit (Adwan, 2014).

Nurse managers and staff nurses in leadership roles should practice intentional acknowledgement of the nurse's experience and potential grief (Kain, 2012). This includes seeking out individual nurses to offer support and inquire about their well-being. Offering personalized, situation-specific positive feedback, as well as the opportunity to verbalize feelings fulfills nurses' desires of an acknowledgment of burden (Anderson et al., 2015; Kain, 2012; Lee and Dupree, 2008). A follow-up telephone call may communicate further empathy and support. This may also be the best time to offer employee grief counseling options. Nurses report the desire to have support offered, rather than seek it out themselves (Kain, 2012).

Nurse managers may be challenged to cultivate a sense of community surrounding the potential stress and grief of caring for critically ill and dying babies. Outward displays of emotion and grief are anticipated and accepted within an environment of grief support (Hildebrandt, 2012). Staff meetings or daily rounds may be opportunities to insert these activities into the culture of the NICU. Provision of a small, quiet room within the unit for meditation, prayer, or crying is supportive to staff. Memory walls located in the staff lounge or community space acknowledge the loss of babies and the nursing care they received (Aycock and Boyle, 2009; Houck, 2014).

Debriefing

Formal debriefing may be beneficial in grief support. The most positive effects are gained when debriefing is experienced as quickly as reasonably feasible following the death. Preference should be given to the work schedule of the nurse serving as final comforter (Kain, 2012; Mendel, 2014). Existing policy and procedure for the initiation of debriefing may reduce lag time in scheduling a debriefing session. Philosophical and logistical support is crucial in demonstrating to staff that grief support is valued. Facilitation of grief support includes providing a comfortable and private space, paid-time off for participation, and resources to maintain staffing in the NICU. The encouragement and ease of attendance of debriefing sessions have been viewed by some administrators to increase nurse satisfaction and decrease turnover (Keene et al., 2010).

Debriefing facilitators should have expertise with grief management. Trained group leaders are skilled to recognize potential complications and identify members who may need more assistance. Experienced leaders create a safe and trusting environment more easily, resulting in the most productive use of time (Keene et al., 2010). Corporate employee assistance counselors may be utilized as grief counselors in some instances (Aycock and Boyle, 2009). Interdisciplinary sessions allow for multiple perspectives, encouraging both a celebration of loving care and discussion of opportunities for improvement (Keene et al., 2010).

Conclusion

Nursing literature supports anecdotal evidence that caring for infants near the time of death is an emotionally intense experience (Kain, 2012; Mendel, 2014). In the event of an infant death without the presence of parents or other family members, the bedside nurse has the opportunity to offer the baby love and comfort while providing physiological support. The plan of care for this circumstance is complex, and nurses may experience moral distress if they feel overwhelmed or unable to meet the infant's physical, emotional, and spiritual needs (Mendel). NICU nurses who receive education on grief management and palliative care, mentorship from experienced nurses, and post-mortem grief support are better able to manage their own experiences with grief after the death of a patient.

Nursing administration, staff, and the individual nurse maintain a responsibility to provide education, orientation, and support to those nurses who may care for a dying infant in the role of final comforter. Although an infant death, especially in the absence of parents, can create a dark and melancholy atmosphere, the comfort and support of colleagues who have experienced a similar event can promote an atmosphere of love and care for babies and their nurses.

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